

# Original Research

## US women's attitudes to false-positive mammography results and detection of ductal carcinoma in situ: cross-sectional survey

**ABSTRACT** ● **Objective** To determine women's attitudes and knowledge of both false-positive mammography results and the detection of ductal carcinoma in situ after screening mammography. ● **Design** Cross-sectional survey. ● **Setting** United States. ● **Participants** A total of 479 women aged 18 to 97 years who did not report a history of breast cancer. ● **Main outcome measures** Attitudes and knowledge about false-positive results and the detection of ductal carcinoma in situ after screening mammography. ● **Results** Women were aware that false-positive results do occur. Their median estimate of the false-positive rate for 10 years of annual screening was 20% (25th percentile estimate, 10%; 75th percentile estimate, 45%). The women were highly tolerant of false-positive results: 63% thought that 500 or more false-positives per life saved was reasonable, and 37% would tolerate a rate of 10,000 or more. Women who had had a false-positive result (n = 76) expressed the same high tolerance: 30 (39%) would tolerate 10,000 or more false-positives. In all, 62% of women did not want to take false-positive results into account when deciding about screening. Only 8% of women thought that mammography could harm a woman without breast cancer, and 94% doubted the possibility of nonprogressive breast cancers. Few had heard of ductal carcinoma in situ, a cancer that may not progress, but when informed, 60% of women wanted to take into account the possibility of it being detected when deciding about screening. ● **Conclusions** Women are aware of false-positive results and seem to view them as an acceptable consequence of screening mammography. In contrast, most women are unaware that screening can detect cancers that may never progress but think that such information would be relevant. Education should perhaps focus less on false-positive results and more on the less-familiar outcome of the detection of ductal carcinoma in situ.

### INTRODUCTION

Screening mammography is vigorously promoted in the United States. With the exception of the US Preventive Health Services Task Force, most professional organizations recommend that women begin annual or biannual screening at 40 years of age.<sup>1-3</sup> Mammography is promulgated by hospitals, insurance plans, and breast care centers. Efforts for quality improvement commonly focus on increasing the screening rates for breast cancer, and health plans highlight these rates on cards used for reporting quality of health care. Although the possible benefits of mammography have been much discussed, the possible harms have not.

The harm that has received the most attention is false-positive results. Mammograms that give false-positive results are common. A 60-year-old woman screened annually for 10 years has about a 50% chance of having at least 1 false-positive that leads to follow-up testing and about a 20% chance of a false-positive that leads to biopsy.<sup>4</sup> Consequently, many people are concerned about the physical, psychological, and economic costs of false-positive results.<sup>4-10</sup> Several experts in screening have concluded that women would benefit from education about false-positive results if they are to make informed decisions about whether to undergo, or to continue with, screening.<sup>2,11-13</sup>

Little attention has been paid to the increasingly more frequent detection of ductal carcinoma in situ, a subtle but

possible harm of screening.<sup>14</sup> Although the clinical course of ductal carcinoma in situ is poorly understood, most lesions do not progress.<sup>14-17</sup> Consequently, more women with lesions that would never have become clinically apparent are worried about cancer, and most will undergo invasive treatment of unknown benefit (for example, mastectomy or lumpectomy with radiation).<sup>14</sup>

Whether or how women offered screening are being counseled about false-positive results and ductal carcinoma in situ is not known. To determine what women know, we conducted a national survey of US women, a population with high exposure to mammography—more than 85% of US women aged 40 years or older have had at least 1 screening mammogram.<sup>18</sup> We wanted to find out if women are aware of false-positive results and if they have a sense of the chance of having 1, if false-positive results are tolerated because women have an unrealistic sense of the benefit of mammography, and if women are aware of ductal carcinoma in situ and, if not, whether they want to know about it.

### PARTICIPANTS AND METHODS

#### Design

We randomly selected women from details compiled from telephone directories and administrative records (for example, applications for a driver's license, electoral registries, and house purchases) by National Decision Systems,

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### Summary points

#### What is already known on this topic

- False-positive results and diagnoses of nonprogressive cancer are recognized problems of screening mammography
- Little is known about how women feel about these problems

#### What this study adds

- Almost all (99%) of 479 women knew that false-positive mammograms occur
- Women do not seem to think false-positive mammograms are an important harm of screening—even women who have had a false-positive result
- Women's tolerance for false-positives is not explained by overly optimistic beliefs about the benefit of mammography
- Few (6%) of the women were aware of the possibility of nonprogressive cancer

Atlanta, GA. We restricted our sample to the 80% of US women in households with telephones. We used stratified random sampling to oversample women of screening age. Specifically, we selected women by age (18-39 years old, 200 women; 40-49, 250; 50-69, 250; and 70 or older, 100), estimated income (income more or less than twice the 1992 poverty threshold for a family of 4 people<sup>19</sup>), and area of residence.

From August to October 1997, we mailed a questionnaire (with \$2 as an incentive) to 800 women. We chose to conduct a postal survey to use visual analogue scales. We mailed reminder letters to nonrespondents after 2 weeks, sent a second copy of the questionnaire after 4 weeks, and attempted to telephone those who had still not responded after 6 weeks.

Of the 800 people selected, 33 were ineligible (21 had died, and 12 were men) leaving 767 possible respondents. Of these women, 55 had incorrect addresses, 2 did not speak English, and 207 did not return the questionnaire. Overall, 503 of the 767 women (65.6%) returned completed questionnaires. We report on the 479 respondents with no history of breast cancer.

### Survey

We developed a 13-page questionnaire as part of a larger project on women's decision making about mammography. A pilot was tested on women veterans served by the Veterans Affairs Medical Center at White River Junction, Vermont.

### Visual analogue scales

We asked women to estimate the sensitivity and false-positive rate of mammography with a previously validated visual analogue scale.<sup>20</sup> To familiarize respondents with

the scale, we included 2 practice questions about events having extreme probabilities. Overall, 94% of respondents used the correct end of the scale for each event—close to 1 for the chance of stopping at a red light, and close to 0 for the chance of being hit by a meteorite.

We also asked women to compare the benefits of mammography with other preventive activities that might extend the life of a 60-year-old woman (figure 1). For each prevention strategy, we asked respondents to mark anywhere on a line scaled from “much less benefit” to “much greater benefit” compared with 10 years of annual mammography, the midpoint being “same benefit.” We measured the distance of each woman's mark from “much less benefit” and calculated the median value.

### Analysis

Because we used stratified random sampling, we calculated sample weights to account for the probability of selection and to compensate for small differences in response rates across sample strata. We then adjusted the sample distribution to conform to known marginal distributions of the US population, based on data from the 1990 US census,<sup>19,21</sup> by creating “balance weights.”<sup>22</sup> Because the crude results and the weighted results yielded almost identical results, for simplicity we present the crude data. Based on our sample size, we estimate the margin of error of the results to be 4% to 6% in either direction.<sup>23</sup> All analyses were done with commercially available software (STATA; Stata Corporation, College Station, TX).

## RESULTS

### Sample characteristics

Table 1 shows the characteristics of the women. Respondents were from all 50 states and the District of Columbia. Most women reported having had at least 1 mammogram: 35% of women younger than 40 years, 87% of women in their 40s, 93% of women aged 50 to 69 years, and 87% of women aged 70 or older.<sup>3</sup> Similarly high proportions of women planned to have a mammogram in the next 2 years.

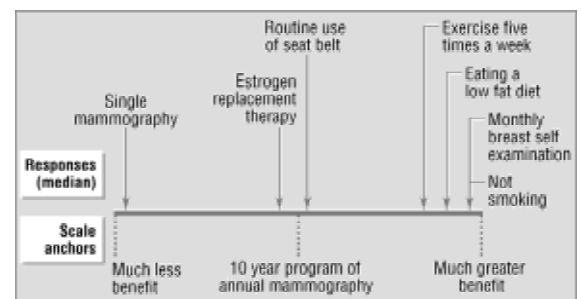


Figure 1 Women's ranking of benefits of health-promoting activities and 10-year program of mammography for extending life in a 60-year-old woman. Arrows show median response for each strategy.

Table 1 Characteristics of sample compared with women 18 years and older from 1990 US census\*

Characteristics	Patients (n = 479)	1990 US census, %
Age, yr		
18-39	120 (25)	46
40-49	153 (32)	16
50-69	158 (33)	24
≥70	48 (10)	14
Ethnicity		
White	431 (90)	78
African American	19 (4)	11
Hispanic	10 (2)	7
Other	19 (4)	4
Household income, \$		
<10,000	24 (5)	13
10,000-24,999	86 (18)	24
25,000-49,999	158 (33)	33
50,000-99,999	163 (34)	22
≥100,000	48 (10)	8
Highest level of education		
<High school graduate	29 (6)	25
High school degree	268 (56)	53
College degree	139 (29)	17
Postgraduate degree	43 (9)	5
Region		
Northeast	67 (14)	21
Midwest	115 (24)	24
South	153 (32)	35
West	144 (30)	20

\*Values are numbers (percentages) unless stated otherwise. 95% confidence intervals ranged from 4% to 6% in either direction for all percentages.

### Perception of harm

Overall, 441 (92.1%) women believed that mammography could not harm a woman without breast cancer (table 2). Of the 38 women who thought harm was possible, 30 responded to our request for an explanation. The most common responses were exposure to radiation (16 women), stress or anxiety (4 women), and false-positive results (3 women). None mentioned the effects of treating nonprogressive cancer.

### False-positive results

Overall, 99% of women believed that false-positive results (ie, abnormal mammogram that leads to a breast biopsy that turns out negative for cancer) occur during a 10-year program of annual mammography beginning at age 60 years. The women's median estimated chance of a false-positive result during such a program was 20%. This estimate is in line with a recent report citing a 10-year 47% probability of a false-positive mammographic result leading to any follow-up testing for a 60-year-old woman and a 19% probability of a false-positive mammographic result leading to a biopsy.<sup>4</sup>

To understand the importance of false-positive results, we asked respondents whether they wanted to take into account such results when deciding about mammography; only 38% did. When asked how many false-positives would be acceptable for each life saved, women showed a high tolerance: 63% would tolerate 500 or more false-positives, and 37% would tolerate 10,000 or more (figure 2). The best estimate of the actual number of false-positive mammograms for each life saved is somewhere between 30 and 200, assuming 2 to 6 lives saved for every 1,000 women screened for 12 years<sup>24,25</sup> and a 10-year false-positive rate between 20% and 40%.<sup>4</sup> Thus, the actual number of false-positives is far below the number most women deemed acceptable.

Women who had had a false-positive mammogram expressed a similarly high tolerance for false-positive results. Seventy-six women (16%) reported having had a false-positive mammogram—that is, a breast biopsy but no diagnosis of breast cancer. In this subgroup, 71 (93%) believed that mammography could not harm a woman who turned out not to have breast cancer, 27 (36%) wanted to take false-positives into account when deciding on screening, 54 (71%) would tolerate 500 or more false-positives per life saved, and 30 (39%) would tolerate 10,000 or more (figure 2).

### Perception of benefit

To explore whether this high tolerance reflected an unrealistic sense of the benefit of mammography, we examined perceptions of benefit. As expected, most women (94%) thought that women whose breast cancer was diagnosed by screening mammography benefited from having been screened (table 2). Although most believed that mammography reduced the chance of dying of breast cancer, none thought it reduced the risk to 0. The most common expectation was that mammography would reduce the chance of dying of breast cancer by half, and the second most common expectation was that it would reduce the chance by a third<sup>24,25</sup> (we considered this to be the correct answer, but a recent study suggests that a one-third reduction in risk may be an overestimate<sup>26</sup>). Women were aware that mammography did not find all cancers. Their median estimated sensitivity for a single mammogram (for a 60-year-old woman) of 73% underestimated the reported sensitivity of 94% (95% confidence interval, 83%-99%).<sup>27</sup>

Most women (82%) recognized that a 10-year program of mammography was more beneficial than single mammography (figure 1). Women rated health-promoting strategies like not smoking, exercising regularly, and eating a low-fat diet as much more beneficial than mammography. Surprisingly, women believed breast self-examinations to be more beneficial than the 10-year program of annual mammography.

Table 2 Women's perceptions of benefits and harms of screening\*

Perception	No. (%) of patients
<b>Perception of harms</b>	
Do you agree that "if a woman getting mammograms turns out not to have breast cancer, she may have been harmed by the mammograms"?	38 (8)
<b>False-positives</b>	
"Imagine a typical, healthy 60-year-old woman. Assume that you know nothing else about her. Suppose that this 60-year-old woman has yearly mammograms for the next 10 years and she does not have breast cancer. What is the chance that she will have a 'false alarm' where 1 of her mammograms will look like she has cancer even though she doesn't?"	Median 20/100, 25th percentile = 10%, 75th percentile = 48%
"Is information about false alarms something you want to factor into your decision about getting a mammogram"?†	182 (38)
<b>Nonprogressive cancer</b>	
Do you agree that "some types of breast cancer grow so slowly that even without treatment they would not affect a woman's health"?	34 (7)
Presentation of ductal carcinoma in situ (DCIS) information‡: "Have you heard about DCIS before this survey?"	29 (6)
"Is information about DCIS something you want to factor into your decision about getting a mammogram"?†	287 (60)
<b>Perception of benefits</b>	
Do you agree that "if a woman getting mammograms turns out to have breast cancer, she may have benefited from the mammograms"?	450 (94)
<b>Sensitivity of mammography</b>	
"Imagine a typical, healthy 60-year-old woman. Assume that you know nothing else about her. Now imagine that this 60-year-old woman has breast cancer but no obvious symptoms. What is the chance a mammogram will find the cancer?"	Median 73/100, 25th percentile = 50%, 75th percentile = 86%
<b>Magnitude of benefit</b>	
"All things being equal, if this 60-year-old woman got yearly mammograms for the next 10 years, she would have . . ."§	
A higher or unchanged chance of dying of breast cancer	34 (7)
A lower chance of dying of breast cancer	
By one fifth to one tenth	62 (13)
By one third	120 (25)
By a half	263 (55)
Reduced to zero	0 (0)

\*95% confidence intervals ranged from 4% to 6% in either direction for all percentages. Questions preceded by "do you agree that" used a 5-point Likert scale (strongly agree to strongly disagree); the proportion agreeing are those who answered "strongly agree" or "agree."  
 †Percentage of women answering "yes."  
 ‡Women were given a brief explanation of ductal carcinoma in situ as a lesion that does not always progress to invasive cancer.  
 §Actual response choices were: lower by one half, lower by one third, lower by one fifth to one tenth, no change, higher by one fifth to one tenth, higher by one third, higher by one half.

**Nonprogressive cancer**

Few women knew about the possibility of nonprogressive breast cancer (table 2). Only 7% agreed that some breast cancers grow so slowly that even without treatment they would not affect a woman's health. We gave the following brief explanation of ductal carcinoma in situ:

We would like to ask your opinion about ductal carcinoma in situ, or DCIS, a breast abnormality that can only be picked up by mammograms. Cancer specialists are confused about DCIS because sometimes it becomes invasive and sometimes it doesn't. If DCIS does not become invasive, it will not affect how long a person will live even without treatment. Doctors don't know which DCIS will become invasive. Nowadays, almost everyone with DCIS gets treated. Many people receive surgery, chemotherapy, or irradiation who would never have gotten sick. For these people, treatment provides no physical benefit.

Only 6% of women reported having heard of ductal carcinoma in situ by name or corresponding to the description provided, and 60% wanted to take ductal carci-

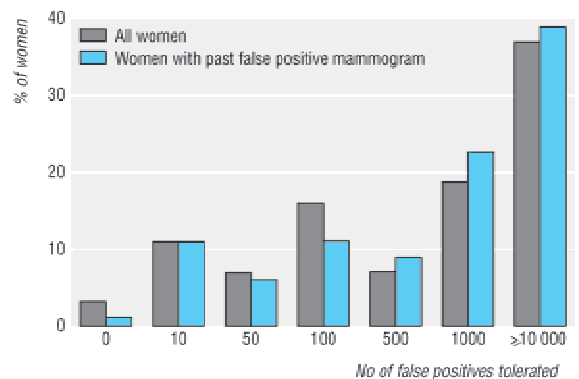


Figure 2 Number of false-positive results women were prepared to tolerate for each life saved

noma in situ into account when deciding about mammography, with interest highest among younger women (71% of women aged 18-39 years).

To assess how information about nonprogressive cancer might influence decision making, we asked women to decide about treatment of ductal carcinoma in situ under different assumptions of its probability of becoming invasive (figure 3). In the hypothetical scenario, more women chose treatment as the chance of invasion increased. At a 1% chance of ductal carcinoma in situ becoming invasive, 42% of women chose treatment whereas at a 33% chance of invasion, 78% chose treatment. The limited published estimates of the chance of ductal carcinoma in situ becoming invasive vary and are as high as 33%.<sup>14,17</sup>

## DISCUSSION

The women in our study were aware of false-positive results from screening mammography but seemed to view them as an acceptable consequence of screening. Although studies attest to the short-term physical and psychological effects of false-positive results,<sup>5-9</sup> our respondents were highly accepting of them: most would not take them into account when deciding about screening, and almost 40% would tolerate 10,000 or more false-positives requiring biopsy for each life saved.

One explanation for this high tolerance is that women have an overly optimistic sense of the benefit of mammography. We found no evidence to support this explanation. No respondent thought screening mammography eliminated the chance of dying of breast cancer. Women were aware that mammography misses some cancers (actually underestimating the reported sensitivity). Most women also recognized that health-promoting behaviors like not smoking, exercising regularly, and eating a low-fat diet were more beneficial than mammography in prolonging life, which is true for the average 60-year-old woman.<sup>28</sup>

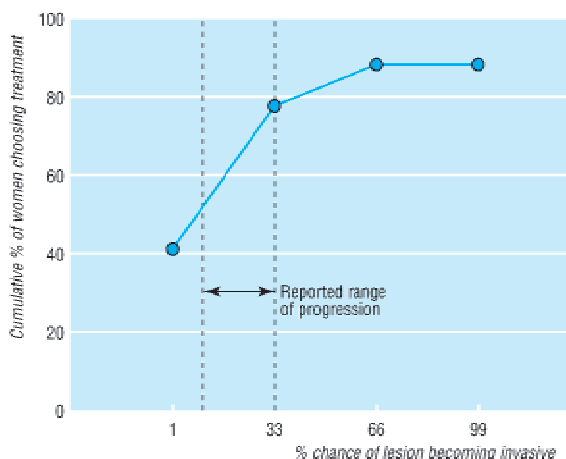


Figure 3 Women's threshold for treatment of ductal carcinoma in situ according to its chance of becoming invasive



Mammography is vigorously promoted in the United States

Alternatively, it might be posited that women did not fully understand the consequences of a false-positive result (for example, anxiety, pain, inconvenience, or extremely rare harms such as severe infection or death related to anesthesia). We found, however, that women who had had false-positive mammograms expressed the same high tolerance as women who had not. Thus, women seemed to believe that false-positive results are worth the reassurance of being told they do not have cancer. Similarly, Gram and colleagues found that almost half of women with false-positive mammograms viewed the experience as having an overall positive effect on their lives,<sup>8</sup> and most women continue to undergo mammography.<sup>29</sup>

Women's perceptions about a possible diagnosis of ductal carcinoma in situ differed noticeably from their perceptions about false-positive mammograms. In contrast to false-positives, most women were unaware of nonprogressive forms of breast cancer and even doubted their existence. Once informed about nonprogressive cancer, the women seem concerned. Most wanted to take into account the possibility of ductal carcinoma in situ when deciding about screening. Younger women, for whom 90% of the cancers found by screening mammography are ductal carcinoma in situ,<sup>15</sup> were the most interested in such information. In addition, women's reported willingness to treat ductal carcinoma in situ increased as we hypothetically increased the chance of ductal carcinoma in situ progressing to invasive breast cancer, suggesting that such information might influence decisions.

## Limitations

One limitation of our study is the representativeness of the sample: we did not include women in households without a telephone and those who requested that their name be removed from the database. This left about 80% of US women eligible for sampling. Second, although our sample represents women across a broad range of age, education, and income, it differed from the general popu-

lation: the women who responded were wealthier, better educated, and almost all were white. Minority women and women with the lowest socioeconomic indicators were underrepresented. Subsequent studies are needed to assess whether such women have different perceptions.

One concern is the possibility of systematic bias in our sample because respondents differed from nonrespondents. Our response rate of 66% lessens but does not eliminate this concern. Respondents and nonrespondents did not differ by age (the 1 variable available for comparison). Our main findings were extreme enough (for example, only 7% of women were aware of nonprogressive breast cancer), however, that even if respondents and nonrespondents differed noticeably, our overall conclusions should remain robust. Although the survey was long and complex, response rates for items were high. Response rates were lowest for the question on the treatment threshold for ductal carcinoma in situ (82%) and averaged 98% for all other questions.

Although experts on screening have focused much attention on the anxiety experienced by women with false-positive mammograms,<sup>13</sup> clinicians counseling women about mammography should spend less time reviewing what most women know and accept—that is, that false-positives are part of screening. In contrast, more time should probably be spent educating women about the less familiar outcome of the ambiguity associated with the detection of ductal carcinoma in situ.

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